

Disability Culture: A Decade of Change

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Abstract: A reflection on the life of David Pfeiffer, why the Center on Disability Studies decided to begin this journal, and what we hope to achieve with it, leading into a forum about disability culture.

Keywords: David Pfeiffer, disability culture, *Review of Disability Studies*

This is a bittersweet forum for me. When a group of us at the Center on Disability Studies at the University of Hawaii at Manoa sat down together to plan this journal and this issue, David Pfeiffer led us.

We planned to follow David's leadership for a long time. Alas, that was not to be. David passed away suddenly in December 2003. We lost our leader.

Each of us feels David's loss in different ways. I'm still discovering ways I miss him. In the first days after his passing, I missed my friend. Someone who lived only a few miles from us and was easy to see whenever we could arrange it. I also missed my colleague. Someone who attended meetings sporadically in the past couple of years, and who credited our being here with permitting him to do that. And, we in turn, thanked David for bringing us to Hawaii. He invited us to present at a symposium in early 2002. We loved Hawaii and the people we met, and with encouragement, we moved here a few months later.

When David did attend meetings, he was zealous about it, bringing with him not only his passion, but a full agenda. I always wondered how our one or two hour meetings could be completed when I read what David had in mind for us to do—and knowing how talkative (and argumentative) we all could be. To my amazement, we somehow did it.

I'm not of David's generation. He was about twenty years older than I. He is the first person I heard talk about Franklin D. Roosevelt being a role model for him as a child who survived polio.

David, in turn, became a role model for many others. This became crystal clear in the days after his passing, when dozens of people shared memories and discussed how much they would miss him.

I recalled the first disability rights meeting I attended in the early 1980s when someone turned to me and talked about the need for "new blood" in the state's disability rights movement. I looked at him in astonishment and wondered what was I?

I'm no longer "new blood" or anything close to that. With David's passing it dawned on me that I have a responsibility to carry on his legacy of mentoring. I'd like to think I've done my share of guiding over the years, but as I age my thinking about mentoring has changed—and David has a lot to do with that.

While I prepared myself to write this introduction I realized something about my relationship with David. He was always enthusiastic about everything I ever wrote. I know from long conversations with him that he didn't always agree with me. Indeed, it's probably fair to say that we had some basic philosophical differences about life itself.

But we also shared a fundamental agreement about life as a person with a disability. We both knew that disability was a socially constructed identity. We also both knew that disability

was not only external—we shared some internal physical manifestations of our different disabilities. We also both believed with a passion in the existence and efficacy of disability culture.

David, at least in his final couple of years, liked to think of himself as curmudgeonly. He called himself “mean” and a few other things that were less than flattering. But the David I knew was one of the nicest, gentlest, and yet most passionate people I have ever met.

He was also one of the most honest. If you said something he disagreed with, he let you know. He didn’t hesitate to speak up at meetings to confront someone. But he was also quite conscious of whom he challenged. If it was an older and respected scholar, he’d take you on vehemently. If you were a young student or emerging scholar, he’d try to be gentle, get his point across, and encourage you to continue your work.

It’s a little less than a week, as I write, that David passed on. I’ve grieved each day. I thought about him most days as I went to sleep and as I woke. I turned on my computer and read email messages about David every day for a week. I’m fighting back tears as I write, not because I don’t want to cry, but because I want to see the computer screen.

And yet... I don’t wish only to mourn for the work my colleague had not completed. I don’t want only to grieve for the friend I will no longer see. I desire also to celebrate.

I want to celebrate a life that made a difference to a lot of people all around the globe. I want to celebrate a life full of love and friendships. I want to celebrate a life lived with zest. I want to celebrate my friend. Which leads me back to the subject of this forum.

David was one of the first people to write about disability culture. When in the mid- to late-1980s this idea of disability culture began to jell with me, I started reading whatever I could that might relate to it.

I found two articles from the 1984 Conference of the Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE, now the Association on Higher Education and Disability, or AHEAD). The presenters were David Pfeiffer, then at Suffolk University and Andrea Schein, then of the University of Massachusetts-Boston. Each asked, “Is There a Culture of Disability?” Their affirmative responses were published in the Association’s *Proceedings*.

Years later I also read an article by Vic Finkelstein, of England after having fled South Africa, published about the same time as the AHSSPPE articles. Like David and Schein, Finkelstein argued for the existence of disability culture.

In the late 1980s, when I first approached my friends and colleagues about the concept of disability culture, I had yet to read any of these articles. I still don’t know exactly where I formulated my initial ideas about disability culture, but as best I could reconstruct them while I wrote *Investigating a Culture of Disability*, I combined my background as a historian interested in reform movements with my reading of grassroots magazines like the *Disability Rag* (now the *Ragged Edge*). And as the three articles by Pfeiffer, Schein, and Finkelstein demonstrate the idea was in the air.

I tentatively approached a couple of meetings in the late 1980s and early 1990s to explore my ideas about disability culture. I received mixed, but always passionate, reactions. I knew I had touched some kind of core about what people believed and I plowed on.

During the 1990s I talked, wrote, and promoted disability culture in any way I could. I wanted to be clear about my own biases and always tried to be honest about them. In my 1997 review of the literature, “Oh, don’t you envy us our privileged lives?” a review of the disability culture movement,” I wrote:

- 1) When discussing disability culture I focus on cross-disability culture, meaning a movement that crosses all disabilities and all cultural groups. I do not do this because I believe the meaning of disability culture is the same for everyone, but because I (and the discussion) have to start somewhere;
- 2) I write about disability culture primarily in the United States, because, once again, one has to start somewhere. There is a thriving, energetic, intellectual discussion of disability culture in England. One of these days I hope to experience it firsthand and write about it. The concept of disability culture has also excited people of every nationality that has encountered and discussed it;
- 3) I examine primarily a British—influenced middle class history and culture. The reason for this is endemic to American history. This background has permeated our national history, politics, culture, and most importantly, the people who have recorded it. It is in part a reaction to this characteristic of our academic settings that disciplines such as social and cultural history, ethnic studies, and women's studies developed. It is also one of the primary motivations for the development of disability studies. Discussions of disability culture from a non-British-based, non-middle class perspective are as needed as they are for other topics;
- 4) I have always been a fan of both high—and lowbrow culture. I am also an advocate of blending academic research and knowledge with non-academic research and knowledge and endeavor to write from that slant;
- 5) I am a white, middle class male and am writing from that perspective.

When we planned this journal, and this forum, we endeavored to address some of these biases. Perhaps the most important tendency we tried to avoid was being Anglocentric. We were not as successful as we would have liked. The primary reason for that was the deadline created for this issue. We worked with people from Japan, Korea, Spain, Malaysia, and the Micronesian island of Chuuk. None were able to contribute in the timeline discussed. We hope to hear from each of these countries in the future. We also welcome reader input and suggestions for writers, especially those with an international background.

We did have some success in broadening this forum. We include contributors from Canada and Germany. While most articles remain cross-disability ones, there is some emphasis on specific cultures, especially Deaf culture.

The articles in this forum reflect thriving disability cultures. We are lucky to have David Pfeiffer's final words about disability culture guiding us as we move into the future. *RDS* is also privileged to include Tony-award winning playwright, Mark Medoff, in our inaugural issue. His reflections about Hollywood and deafness will ring true to many of us who have not experienced the dizzying heights of fame he's achieved.

Perhaps the youngest of the contributors is Jillian Weise, a multi-talented artist, who's appeared in the pages of the *Atlantic*, as well as now gracing us with her observations about disability culture.

Ottmar Miles-Paul is recognized as one of the premier leaders of the German disability rights movement. We are fortunate he took time off from his busy advocacy and journalism schedule to introduce us to a German disability culture festival.

Academic scholars, Stephen Gilson and Elizabeth Depoy, explored the concept of disability culture from the vantage of people with disabilities who do not necessarily identify with a disability rights movement. Their conclusions will challenge us all.

Tanis Doe, like David Pfeiffer, is a thinker who possesses the rare ability to critique where she finds herself academically, movement wise, and culture wise. She has taken on the daunting task of trying to link Deaf and Disability cultures.

Last, I've tried to tie together some of my experiences as a proponent, writer and talker about disability culture for the past decade or so.

We hope that this forum will engage you, challenge you, and motivate you. Just like our friend and colleague, David Pfeiffer, always did.

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STEVEN E. BROWN, co-founder, Institute on Disability Culture, and Resident Scholar at the Center on Disability Studies at the University of Hawaii at Manoa earned a doctorate in history in 1981 at the University of Oklahoma. Brown's most recent publication, *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride* (People with Disabilities Press, 2003), joins dozens of articles and five previous monographs about disability, including *Independent Living: Theory and Practice* and *Freedom of Movement: Independent Living History and Philosophy*. Also an award-winning poet, Brown has published six books of poetry, including *Dragonflies In Paradise: An Activist's Partial Poetic Autobiography*; and *Pain, Plain--And Fancy Rappings: Poetry from the Disability Culture*.

